



HEALTH, COMMUNITIES, DISABILITY SERVICES AND DOMESTIC AND FAMILY VIOLENCE PREVENTION COMMITTEE

Members present:

Mr AD Harper MP (Chair)
Mr MC Berkman MP
Mr MA Hunt MP
Mr MF McArdle MP
Mr BL O'Rourke MP
Ms JE Pease MP

Staff present:

Mr R Hansen (Committee Secretary)
Ms M Salisbury (Assistant Committee Secretary)
Ms A Groth (Assistant Committee Secretary)

PUBLIC HEARING—INQUIRY INTO AGED CARE, PALLIATIVE CARE, END-OF-LIFE CARE AND VOLUNTARY ASSISTED DYING

TRANSCRIPT OF PROCEEDINGS

FRIDAY, 5 APRIL 2019

Brisbane

MONDAY, 5 APRIL 2019

The committee met at 9.31 am.

CHAIR: Good morning. Welcome to the public hearing of our health committee to undertake an inquiry into aged care, palliative care, end-of-life care and voluntary assisted dying. Before we start could I request that mobile phones are switched off or are on silent. I now declare this public hearing of our committee open. I would like to start by acknowledging the traditional owners of the land on which we meet. I am Aaron Harper, the chair of the committee and member for Thuringowa. The other members of the committee with me are Mr Mark McArdle, the member for Caloundra and our deputy chair; Mr Michael Berkman, the member for Maiwar; Mr Marty Hunt, the member for Nicklin; Mr Barry O'Rourke, the member for Rockhampton; and Ms Joan Pease, the member for Lytton.

This inquiry into aged care, end-of-life care, palliative care and voluntary assisted dying was referred to our committee on 14 November 2018. The committee is required to report on the inquiry by 30 November 2019. Today we will hear from representatives of the Queensland Specialist Palliative Care Services Medical Directors' Group on palliative care in Queensland, followed by a short break. We will then receive a briefing from representatives of the Department of Health on advance care planning.

There are just a few procedural matters before we start. The committee is a statutory committee of the Queensland parliament and as such represents the parliament. It is an all-party committee which takes a nonpartisan approach to its inquiries. This public hearing and briefing are formal proceedings of the parliament and are subject to the Legislative Assembly's standing rules and orders. The committee will not require evidence to be given under oath, but I do remind witnesses and briefing officers that intentionally misleading the committee is a serious offence. All those appearing this morning have been provided with a copy of the instructions so we will take those as read.

This public hearing is being recorded and transcribed by Hansard and witnesses will be provided with a copy of the transcript. It will also be broadcast live on the parliament's website. For any media present, I ask that you adhere to my directions as chair at all times. The media rules are endorsed by the committee and are available from committee staff.

I remind those in attendance today that these proceedings are similar to parliament to the extent that the public cannot participate. I remind members of the public they may be admitted to or excluded from the hearing at the committee's discretion. You may also be filmed or photographed and images may appear on the parliament's website.

BROADBENT, Dr Andrew, Queensland Specialist Palliative Care Services Medical Directors' Group

CRUIKSHANK, Dr Ross, Queensland Specialist Palliative Care Services Medical Directors' Group (via teleconference)

GOOD, Dr Phillip, Queensland Specialist Palliative Care Services Medical Directors' Group

HERBERT, Dr Anthony, Queensland Specialist Palliative Care Services Medical Directors' Group

PARKER, Dr Greg, Private capacity

STEVENSON, Dr James, Queensland Specialist Palliative Care Services Medical Directors' Group (via teleconference)

WELCH, Dr Louise, Queensland Specialist Palliative Care Services Medical Directors' Group

WHAN, Dr Peter, Queensland Specialist Palliative Care Services Medical Directors' Group

CHAIR: Welcome. It is a significant inquiry that we are undertaking—in fact, an historic inquiry. Palliative care is an important part of healthcare services. From the outset I thank all of you in the roles that you perform in this important space in our inquiry. Thank you very much for your submission. It is quite detailed. It makes a number of recommendations. I might ask Dr Parker if he wants to start. I know that you are appearing in a private capacity. We welcome your comments. It would be nice to hear, for the benefit of the committee, the individual roles each of the doctors might play in delivering palliative care, an opening remark and then we will move to questions.

Dr Parker: I am a palliative medicine specialist based in Brisbane. I am also director of the Metro South Palliative Care Service. I must let the committee know that I am here today in a personal capacity.

Dr Whan: I am also a palliative medicine specialist. I have worked in palliative care since 1990. For the last almost 12 years I have been serving as clinical director of a rural and regional outreach and support service which has covered the old central area health service, so the middle part of Queensland. That has given me, I trust, a close familiarity with the challenges faced by dying people and their families in those communities and those who are seeking to provide health services to them.

Dr Welch: I am currently the clinical director of the Sunshine Coast Palliative Care Service. I started in palliative care in 1992 and developed a palliative care service in Cairns before moving down to the Sunshine Coast 13 years ago.

Dr Broadbent: I am the medical director of specialist palliative care on the Gold Coast. I have come up from New South Wales, where I did a lot of state based service planning. I have been up here for three years, and I have noticed a significant difference between the two. I guess one of my agendas is to try to get a far more coordinated statewide system of specialist and generalist palliative care that will benefit the patients.

Dr Herbert: I am the director of the paediatric palliative care service at the Queensland Children's Hospital, Children's Health Queensland. I have been working with this service, which has a statewide role, since 2008.

Dr Good: I am a director of palliative care at St Vincent's Private Hospital at Kangaroo Point and also a palliative care specialist at Mater Health Services. I work across both the private sector and the public sector in Queensland.

Dr Stevenson: I am the clinical director of the Prince Charles palliative care service in Metro North. I have been working in palliative care since 2002, and in my working life I have worked both overseas—in the United Kingdom, in Liverpool in the north-west of England—for 18 months and three years in the southern part of Adelaide. When I was working as a consultant in South Australia they were going through a similar process to look at statewide plans for palliative care, which was a huge undertaking and was seen as a very important and positive process.

CHAIR: Dr Cruikshank has not joined us via telephone. Thank you very much. That underpins that there are years of experience before us. I take note of 1990. That is when I started in the QATB many years ago. Coming from the Townsville region, I certainly know the difficulties we face in delivering any form of care across our vast state, but some of the commentary we have read in private submissions, which are nearing 2,000, has indicated the difficulties in delivering specialist palliative care right across the regions. Would you like to pare back some of the challenges that you observe in delivering palliative care across Queensland, regardless of your location?

Dr Parker: I think we are privileged to be here. Thank you for the opportunity. If I may paint a picture of the landscape with an opening statement, I think we have achieved remarkable advances in health care with the aid of modern medicine. In spite of this, death is a universal health outcome. I think equitable access to comprehensive palliative care therefore must be recognised as a fundamental human right and an essential component of value based, safe and high-quality health care for all. It cannot and should not be considered an optional extra of health services any longer.

The people who experience a life-limiting illness potentially are and do become the most vulnerable members of our society. We can only imagine how visceral the sense must be for the person, their collective family and informal carers, yet we expect them to navigate their way through the complex healthcare system we thrust at them. As experienced palliative medicine specialists, who together with our nursing, allied health and primary care colleagues are at the coalface of healthcare delivery, we are acutely aware of the gaps and inequity that exist across Queensland in the context of inadequate and disparate resourcing for the provision of a comprehensive palliative care system. To achieve the care that is individualised and concordant with the wishes and values of the person with a life-limiting illness requires planning, it requires delivery of care that is structured, flexible and considered and it requires the availability of responsive services 24 hours a day, seven days a week, irrespective of the setting. We do not have this down right.

It has to be person-centric rather than system-centric. We struggle with that. To achieve this, however, needs more than goodwill; it needs meaningful investment of dollars that is not a patchwork approach. We see too much of that in our practice. I think universal access and delivery of best possible palliative care, independent of prejudices, the postcodes we live in, the time of day or where the person may be in their terminal disease trajectory, requires a concerted effort from government, the healthcare system and the community to really improve the current landscape. We cannot leave this to chance any longer.

I think there remains a huge body of work to be done across the palliative care space—as has been mentioned—to achieve the standards of care required to meet our patients' needs. I think it is commendable to put pen to paper, but translating intent into action with meaningful outcomes is the work that lies ahead of us all, no matter where we are. I think we are hopeful that this inquiry will not go unnoticed and will contribute towards achieving improved accessibility and deliverability of high-quality specialist palliative care to all those who need it and indeed want it. It needs an investment in advance care planning, workforce and infrastructure, with a focus on the patient and family. We need to flatten the amplitude that exists across Queensland and recognise that resourcing palliative care for our dying patients and their families is just as important as investing in other aspects of health care.

Mr Chair, we have presented you with our submission for the committee's consideration. We now offer you our collective specialist narrative and experience. As experts in our field, we know the priorities and believe our speciality is optimally placed to lead the development of specialist palliative care and palliative care, indeed, across Queensland to deliver patient centred, equitable care. We offer pragmatic solutions for a way forward to improving equitable access to comprehensive palliative care for all Queenslanders. However, this will need meaningful engagement and investment in the sector. I think we honestly believe that dying people and their families across Queensland deserve better resourced palliative care.

CHAIR: Thank you very much, Doctor. A sentence on page 1 of your submission begins with, 'Queenslanders continue to struggle to access equitable and needs based palliative care due to' and then you make a number of points. Your third point is a lack of integration between hospital and community based specialist palliative care services. How do you think we improve this?

Dr Broadbent: I will give you a bit more of my background. I have a Master of Health Management. I am one of the few medical clinicians with a professional management degree. Part of the solution to this—and you will need multiple solutions—is that we need a state based coordinated approach that has to be funded to do that. An example is this is the medical directors' group, which came into being less than 12 months ago with Palliative Care Week. We met at Parliament House. Louise, Greg and I talked and said, 'We need this system.' We said, 'Let's set it up.' We have achieved a lot in 12 months. We have met monthly. Greg has been fortunate enough to have some resources to facilitate that—for example, an administrative assistant. This is one of our big projects that we have been working on. Obviously, VAD will be another one. That is an example that you need. We can provide that state based approach. As a group, whether we are regional, as Louise and I are, in Townsville, or metropolitan, or rural, which is where Peter is, we can support each other as clinical directors. We can start strategising things across the state as well as, of course, in conjunction with nursing and allied health staff.

CHAIR: I am glad you brought up nursing. I was at a community forum the other night at Norman Park where a palliative care nurse spoke very well about the hundreds of patients she was looking after the night before. That talks about the specialist workforce with nursing. Do you have an idea of the numbers required? You can take that on notice to provide some feedback. We are trying to get a view on the number of nurses in each HHS. In community based nursing, what numbers might we need in that palliative care space?

Dr Parker: If I may, I can talk about my own service. The difficulty is available data. We struggle with data. Certainly, the Australian Palliative Care Service Development Guidelines are available and give some approximate measures per population base.

Our model in the community palliative care setting is one of a nurse case manager. For example, at the moment we have 12 nursing staff FT deficits to just meet demand. That is only within my area. I cover approximately 3½ thousand referrals a year. We are in the south-east corner of Queensland, in Metro South. It is a huge impost on the staff that is already stretched. I think this is an issue across the state. We need to map what is required.

CHAIR: Welcome, Dr Cruikshank.

Dr Cruikshank: I apologise for my delay, but thank you.

CHAIR: We have just started asking some questions. Did you want to make a brief opening statement and tell us about your background?

Dr Cruikshank: I am a palliative care physician and medical oncologist at Ipswich Hospital. I am the clinical leader for the department of palliative care and medical oncology here. We are part of the West Moreton Hospital and Health Service. We are the hub of that whole area, which is a large area. We service Boonah, Laidley, Esk, Gatton as well as Ipswich itself. Our palliative care service consists of a 13-bed unit with an extensive community support program, with consultants in the community as well as a nurse practitioner. We also do telehealth out to the rural hospitals.

Obviously, from my point of view, I am very interested in making it known from a palliative care perspective in the more rural areas what our needs are as far as resourcing goes. Greg has spoken about widespread issues with resourcing. Certainly the hat I am wearing at the moment is about facilitating good care in the community, dying at home and providing appropriate nursing and medical support for that.

CHAIR: Thank you very much. I will continue with the workforce question that I was asking before. I note on page 3 of your submission, at the second paragraph, you say that in Queensland there are 38.4 full-time medical specialist positions and the required full-time equivalent is 92 positions. That data is accurate?

Dr Parker: Yes. If I may have leave to table the document that was prepared from one of our director members?

CHAIR: Is leave granted? Thank you. Do you want to speak to the document?

Dr Parker: If I could give you context, Carol Douglas is the chair of the Palliative Medicine Training Pathway Oversight Committee, which was established a number of years ago. We sit on that committee. Part of that was to look at mapping the current requirements and workforce deficit, especially with palliative specialists in Queensland and training as well. It all interlinks. Palliative Care Australia's workforce development guidelines indicate a ratio of two specialists per 100,000 of the population. Within the Queensland context, we have then mapped out and gone around all of the areas to look at where the deficits are and what we have available. There is a very good table indicating the current lie of the land. That gives us an indication. That is based on that.

CHAIR: Excellent. That is outstanding. It is good if there is some data that we can point to.

Dr Parker: I think it is important to keep emphasising the point that we need meaningful data.

CHAIR: Before I open to questions from other members, can I take you down the path of aged care. There are synergies in palliative care delivery in residential aged-care facilities, at home and at other institutions throughout Queensland. Can any of you comment on the aged-care funding that is delivered to patients who are unwell, in a palliative care state, that may be delayed and that impacts on the delivery of palliative care? The aged-care packages that are delivered go from levels 1 to 4. Is there any commentary, evidence or observations that you can make in that space?

Dr Welch: Unfortunately, again, the data is lacking. To put it very practically, all of the members here would say that, when we are trying to, for example, discharge someone who has come into an acute hospital setting back to their home environment, who fits the criteria for an aged-care package, being over 65—and the joke is that it was my 65th birthday last week and now I do not have to go through the loops and hoops of the under-65 group; I can now access ACAT and level services. However, if I were palliative throughout the level of packages, if I got one, there is no nursing in that.

CHAIR: There is no nursing—

Dr Welch: There is no hands-on nursing in a level 1 to level 4 package. This is personal hygiene—no nursing skills. The problem we have is that most of our patients will progress very quickly in their needs. They will progress from being independent, able to sit at a table and talk with us, to perhaps being bedridden within months or days. The current packaging and the way the ACAT services are run does not allow for that. Someone may need a level 1 package today but need a level 4 package in a week. They may enter on a level 1 package into a hospital. We have to get them reassessed, then we have to send them home looking for a level 4 package.

The sad practicality is that there is no data, because we know—we do not even bother asking for an ACAT assessment—that if they get a level 4 approval they will die before they get it. The waiting list is variable from place to place. It can be from many months to a year. That depends on how many people with a level 4 package die to free them up in a district. We have a problem where the needs of our patients are not met because they cannot access the personal care equipment and things that they need for the many months that they may be disabled and unwell before they die at home or

elsewhere. Many patients do not get home. In our district we have started to keep some data on the number of patients who we think we could get home if they had immediate access to a level 4 equivalent package plus specialist nurses from district funding, if the family were able to cope. We do not even bother at the moment.

CHAIR: Maybe that is something the group can undertake in its work going forward. Congratulations if it is 12 months old. I think that is a good start.

Mr HUNT: Thank you for your submission. It is pretty concerning reading. One of the themes of it is resourcing. It comes up a lot. Dr Broadbent, you said that you had spent some time in New South Wales and there were some key differences. Is that a better system? If so, why? What are the key differences?

Dr Broadbent: Thank you for that question. Obviously, it is far nicer to live in Queensland than in New South Wales.

CHAIR: I am glad you pointed that out.

Dr Broadbent: I have this issue regularly, because we are on the border. New South Wales is about only 10 kilometres from our palliative care unit and there is a significant flow of patients across the border. I usually use the analogy that if I have five fingers on this hand and five on that one, and what I can get in each state is very different, if I could put them both together I would have a system that supports far more patients than currently happens.

To take Louise's point a bit further, somebody at home in New South Wales has access to a couple of palliative care packages that they do not have here. One is called a ComPacks package. Palliative Care Queensland has put in a submission, as we have, that outlines that they are needed critically. They act as that buffer between leaving the acute care services and when the community package of care can really be activated. As Louise has said, getting a level 4 package for our patients is just near impossible. There is a two-year wait. We know that. Getting level 1 is probably fairly quick, but you are still talking weeks, not hours. That ComPacks package makes a huge difference. Previously, we used to admit into an acute hospital in New South Wales to get the ComPacks package, put them in for one day and take them home again. That was extended then into subacute hospitals, so we did not have to do that. That has made a big difference on the return-to-hospital rate.

The second package, which was driven through a consortium of HammondCare, St Vincent's and Calvary in Sydney—and Silver Chain does something similar—is the end-of-life care package, which essentially is the last week or two. We know—and there are some studies coming out from where I used to direct, which is northern Sydney, and we set this all up probably five or six years ago—that, if in the last week or two of life we can get an extra carer, maybe AIN level or care worker 3 or 4, people stay at home, particularly at night. The reason is that, by that time, everyone is emotionally and physically shattered. They struggle to keep people at home. Over 80 per cent of Australians want to be at home. Families are trying really hard to keep that, but at some stage they get tired. When you cannot up the resourcing, the default is hospital.

We have a number of people who come in for the last week or two of life. Ideally, they would not come in at all. We cannot change the structure of our funding because of how our state based funding is. I cannot create the community teams that I need to keep these people at home or create the package of care. That is one example.

The other example is nursing homes. On the Gold Coast, we historically have not gone into nursing homes. Metro South has a very good model. It is worth replicating. In northern Sydney, where I came from, it was part of normal business practice. What happens in a nursing home is you have the care; you do not have the expertise, the knowledge, to go in at short notice or medium notice. Advance care planning is not done particularly well. The nurses have very little support, as I am sure you know. There may be only a non-RN on site after hours. Access to drugs is very poor. The only default they have is to send them to emergency.

We know that on the Gold Coast every month 30 people from nursing homes come in and die, probably unnecessarily, in the acute hospital, but we do not have systems that can react acutely. New South Wales has a number of programs. There are rapid response teams. The GRACE model is a very good geriatric related model, and other palliative care services have tried to replicate that. When you hear of these issues, if you can respond quickly we can do something.

One of the things that we have done on the Gold Coast to try to facilitate this for the home is to bring in telehealth. Prior to my arrival we did not really do any telehealth. We now do 60 to 80 per month. It allows our senior clinicians, who are usually medical but are also senior nurses, to work with

community nurses and other members of our specialist palliative care team, and we are about to roll it out to Queensland Ambulance on the Gold Coast—the first place in Australia—where, where they are concerned about patients who are known to our service, they can ring through for instant video advice within the usual five- to 10-minute range.

What is hampering us, of course, is the administration support. We can make the clinicians work another 10 per cent harder, but you do not want to make them have to do the secretarial work as well. We have put in grants to try to get that component. Rolling out our tele/video health service to another core key group, the Ambulance Service, who are crucial in keeping people at home, we feel will support that. That will be studied by various people, so I cannot tell you that it will work. My hope is that it will work. We do know from the HammondCare studies done by their team in northern Sydney that extra resources into nursing homes, be it clinical staff or education, keeps people in nursing homes. Rapid response teams keep people in their nursing homes. To keep people at home you need these packages of care.

There are a few examples, if you want cases. I had a 17- to 18-year-old boy with nasopharyngeal cancer. It is a very nasty disease. He has just gone back to south of the border. Pain control is the biggest issue. In Queensland we could give this boy radiotherapy, give him opioids, give him some other treatments, but I could not access an intrathecal. An intrathecal is a fairly complex way of pain relief. In New South Wales I could get that easily. The issue is that that was easy to get in Lismore, but in Queensland it is almost impossible to get something that would be standard of care. If I as a physician cannot get procedures done because there is no state based way of doing this, our care is hampered.

I have had that same discussion with you—funnily enough, you are in the big hospital here but what I need is actually done in your local hospital. We cannot do it. Why? Because it is Queensland. It is one of the things that we are going to be working on as a group—how can we do that? We are working with our pain colleagues. At RBH we have had discussions about how do we create a statewide network to get this done. At least if we could send them to a major hospital that would be helpful, but we cannot even do that really. Cordotomy is another example of a complex procedure that requires a statewide approach.

Mr BERKMAN: Thank you so much for being here. We really appreciate your submission. You touched very briefly on VAD in your submission. Without meaning to dismiss the substance of everything else that is dealt with in the palliative care space, can we take as a given, accept unreservedly, the need for better resourcing in this space? I am very interested in the interface between VAD and palliative care. The differing objectives for palliative care specialists and advocates of VAD sometimes frame it as them being in conflict in some respects. I am interested in understanding your views. While I accept that palliative care can improve the end of life for every patient, what can you tell us about the limits of that and how you see VAD as a policy that we have to consider in light of those limits?

Dr Good: Thank you very much for that question. I think as a group we would all agree that VAD is not part of palliative care practice. That is very much the way we see things. We would all like to make it clear that we do not think that if VAD legislation was to come into Queensland it should be part of palliative practice, nor should it be performed in palliative care services or units across Queensland. I think that has been a misconception in other places where it has come in. There has been this thought that VAD has some overlap with palliative care and therefore it is a natural fit.

The way I think about it is that palliative care is a healthcare service; VAD is a societal issue. I am not sure that VAD is part of health care or part of a healthcare service as such. I think what we really need to put across is that VAD is very separate to palliative care. If you look at studies, people access VAD for various reasons. Very rarely is it for symptom control. That is a really important thing to get across. People do not access VAD overseas for symptom control issues; they access VAD for societal issues, or what I think are societal issues. Those are things like fear of the future, loss of independence, loss of dignity, loss of autonomy—the idea of values. People access palliative care for symptom control issues, for complex psychological issues and things around that. One of the things we need to make clear is that, whether VAD legislation comes in or not, palliative care is committed to looking after patients whatever their choices are in any service from that point of view.

I think there is this idea that there is an overlap. Certainly in other countries—it has not started yet in Australia but in other states it will come in—people may be accessing palliative care or not or they may decide to go down the route of VAD or not from that point of view. There is another misconception that somehow euthanasia or similar things are happening in palliative care. There is this idea that drugs that are used in palliative care somehow shorten someone's life which is just not

true at all. All the research, including research by people in Australia—I have done research on that—is that the use of medications in palliative care, used within clear clinical guidelines, does not shorten anyone's life.

CHAIR: Dr Good, for the benefit of anyone watching, can you talk about what terminal sedation is?

Dr Good: There are various terms used. I think probably the best term is what is called sedation for refractory distress. It is often thought about as pain. People naturally thought about this idea of pain. In fact, sedation for refractory distress is hardly ever used for pain. If you look at studies, it is rarely used. The most common reason that sedation at the end of life is used is probably what is called delirium, where people are dying, their body is shutting down and they are very confused. It is really distressing because you have people who are normally very placid people who suddenly become very agitated and very confused. What is interesting about that in some ways is that delirium is viewed differently in different cultures. In some cultures that confusion, which is very common at the end of life, is seen as a natural part of dying and accepted. In other cultures, especially our culture, it is seen as a form of distress. It is very hard to know because the person cannot tell you whether it is distressing or not.

Commonly we use medications like opioids, such as morphine, and medications to help with anxiety, like Valium type drugs, at the end of life—none of which are directed to make someone unconscious, none of which are directed to make someone have a shorter life. There is a viewpoint somehow that the use of these drugs shortens someone's life. As I say, the research does not show that at all. The research shows that, whether people are getting small doses of these drugs, large doses of these drugs or escalating doses of these drugs in relation to need—to make people more settled, to make people less distressed from that point of view—length of life is no different at the end of life. For most people when we are talking about using sedation for refractory distress we are talking about using medication right at the end of life, in the last hours of life, occasionally the last days of life, but certainly not in the last weeks or months of life. We are not talking about somehow someone's life is a very long period and it becoming a very short period. The really important thing is that that medication is used when people are dying. There is nothing that is going to stop the dying process at that stage. Medication is not going to shorten the process. Medication is aimed to help with the distress.

It is good to think about the differences between sedation for refractory distress and euthanasia or voluntary assisted dying. The first thing is that the drugs used in both situations are very different. To give you an example, for sedation we use drugs like morphine and Valium type drugs, but people do not use that for euthanasia or voluntary assisted dying because they do not work. They do not actually work in that situation, so they are not the drugs used. Initially, many years ago when it first came into places like the Netherlands, they did try to use the drugs that we use in palliative care, but people did not die, so they stopped using them and they use different drugs now which we do not really use in palliative care from that point of view.

CHAIR: You have gone on a very important pathway. We have nearly 2,000 submissions and there are opposing views to your statement. You note that people are lingering for days with terminal sedation. Submitters are complimentary of the palliative care, if it is available. They are extremely grateful for the care that is given, but certainly the ones that I have read are indicating there is immense suffering and some harrowing stories to the point where people are considering taking their own lives. There are a number of other factors in this. I just want to get your views on that. I do not know whether you have read any of the publications in the submissions, but some people would suggest that there is a gap that, even with the very best palliative care, there could be or may be circumstances where they are not getting relief. That is certainly something that we are reading. Do you have any views on that?

Mr BERKMAN: Can I add an addendum do that question: in addition to what the chair has asked, I am interested in how you as palliative care clinicians see the role of choice in end-of-life wellbeing and decision-making and to what extent and whether the availability of VAD affects people's wellbeing in those closing stages of life.

Dr Broadbent: Thank you for those questions. This is a society issue and my feeling is that, as in Victoria, this will happen like we have had with medical marijuana. There have been huge changes in society in the last five years, and they will continue. I think you are right: it is about choices. One of my constant discussions is should I change the name of my team to the 'choices team' because that is part of what we do. What we do want is the ability to give the right choices and the appropriate choices. I was asked the other day to do a consult—and this happens every week. The

choice was nursing home or death by palliative care. The patient decided essentially death by palliative care—'I want to do palliative care; I am going to die in the next couple of days.' The patient was not going to die in the next couple of days. The patient may well live for six to 12 months.

Our role there was to educate the patient, the family and the staff that they were actually not the choices. There are far better choices. The choice of a nursing home should not be seen as something worse than death, but that goes back to my earlier comments that we are sending people to facilities that are underresourced to manage their issues. We do not have the ability in the acute hospitals to keep patients long term, so they are falling through the gaps. The choice they see is that they would rather die than go to a nursing home. Unfortunately, it is a sad indictment of society when they are the choices.

CHAIR: Are there any other views from the doctors on the phones? Is there any other commentary on that point?

Dr Whan: If I could express the personal experience I have had over the years: I have been working in palliative care clearly when, on occasions, a patient or a family member has spoken quite openly with me—sometimes subtly, sometimes quite overtly—to request that we do something to actively shorten or end the patient's life. My personal value commitment is that of biblical Christianity. I do not believe that for me to do that would be moral, or to encourage somebody to take their life would be a moral choice, but it has also been the situation where it has not been a legal choice either. Obviously, your committee is deciding the legality of those issues.

Certainly, I have always felt it extremely important when that question has been raised to engage with the person and with the family. I have generally expressed it in terms of thanking them for being open with me, because it helps me to understand the level of distress they are feeling and the level of concern they have, and it helps me as a clinician, and the team that I am part of, to focus more on addressing the issues. It has been my experience that, when I thank the person for their openness and engage with the issues that they have raised, we have been able to find mechanisms within palliative care practice that have addressed the issues.

That is my personal experience from my own clinical practice. I do not deny that there would be people, as Phillip has said, who for not necessarily clinical reasons, find life burdensome and wish to end it, but I do not believe that that is part of palliative care practice. It is something that you as a committee is tasked with considering.

Dr Good: Palliative care is all about choice. It is one area of health care where we are really trying to make the patient the centre. Our viewpoint is that, until you have an equitable, world-class palliative care system across the state, it seems premature to introduce a pathway that some people may choose to go down when they have not had adequate access to good symptom control. I think that is one of our big concerns.

Dr Herbert: I see your point about autonomy being a strong argument for VAD. That is very much at the individual level, but I think we also need to look at the implications for society as well. Perhaps there are arguments stronger against VAD when we look at the impact on families, society and the healthcare system. I think the autonomy argument also has to be looked at more broadly within the context of the community.

Another point would be that people who are mentally competent to make their own decisions is one thing, but how do we deal with other situations—for example, patients who have dementia and who at that point in time do not have the capacity to make that decision or, in my own area of practice, who are in the under-18 age group. The issues of competency are very complicated when we are also looking at a developing brain and the role of the parents in making decisions.

CHAIR: Do doctors on the phone wish to comment?

Dr Stevenson: I want to back up what Dr Broadbent was talking about in terms of his clinical experience. A lot of work is still required for education, not just for families and carers but even for medical and other health professionals, around what palliative care aims to deliver, what we do and what we not do. Personally, it is just luck that I ended up in palliative care. We had very minimal teaching through our six-year degree when I went through—probably only a handful of hours and that has not changed much. Many people are coming out of health training with little to no exposure to palliative care, so they are left to create their own thoughts on experience, which may not always be accurate. A lot of our work in hospitals is to try to dispel the myths that may have already been shared with patients and families, which can then be very hard to unpick. There are still doctors out there who think that any dose of opioid would shorten someone's life or that what we do in palliative care

is a bit of a wink and a nod and we do not call it something that it is not. We have to spend a lot of time dispelling those rumours. On many occasions we have encountered patients, just like Dr Broadbent has, where they were given some choice which I would call a false choice.

I think choice has to be accurate. Making informed decisions can only be as powerful as the quality of the information that is given to make that choice. A lot more work is required in the field of education for all health professionals who may encounter people with palliative care needs. Part of that would be improved funding and improved resources to help palliative care work better as a true speciality. That would include not just delivering more care to patients but having that role of being a health advocate and a teacher and trainer of others.

Dr Cruikshank: From my personal experience of those who are initially faced with a terminal diagnosis, when I see them from the outset, there are often thoughts expressed about euthanasia and wanting to shorten the process. A lot of time those thoughts, feelings or desires are coming from a lack of knowledge that that support is there. Generally, once they are introduced to a palliative care service and they are reassured that there is going to be that care if they take their entire journey, more often than not they find comfort in that there will be that support. Usually, they then move away from the feeling of wanting to end their life prematurely and are happy to take that journey and feel reassured that we are taking that journey with them. At the same time they will still take that journey on their own terms, but we just empower them to do so.

Dr Welch: In response to some of the submissions that you have received, I have a vivid recollection of a family member who had a patient with us recently who initially requested that we do everything to keep his elderly relative alive. When that did not work, he then said, 'That didn't work, so now I'm asking you to give the green injection.' The reason he stated for that was that it was his perception that his elderly relative was suffering. The elderly relative was now deeply unconscious and was not suffering under any clinical terms. The elderly relative was dying and unconscious, never to wake again, and did die within a day or so without us having to give anything extra. The doses we gave were very small. However, the son felt that it was his duty to reduce the suffering, because he was seeing what he perceived as suffering. The patient was not suffering.

This is what we see repeatedly. It is the suffering of the grief. It is the grief of the person left behind. It is their societal lack of understanding of natural dying, of what dying is about, and now being faced with a painful loss. That is often not recognised. The introduction of palliative care services or supports is part of helping people to come to terms with that journey—usually the carers and the family—if we get them early enough. That often gives—and many studies have shown this—a much better bereavement outcome. If you have traumatised grief, it is usually because of poor supports, or lack of early referral and other things that are out of everybody's control sometimes. Often some of the emotive things that happen after the death of a loved one are grief and loss issues. They have seen someone who is perceived to be suffering.

Dr Parker: I know you are going to do advance care planning after this, but I think such a crucial point is being able to sit down and have the conversation, which is an iterative process. It is conversational rather than tied up in a legal process—'Let's get the job done and have the document.' I think it is important. People come to us and say, 'No-one has spoken to us. No-one has asked us what we want, what our values are, what is important for us at the end of life.' I think that is fundamental. A lot of good work has been done in Queensland with Queensland Health, with the Office of Advance Care Planning. I think it is important and I urge this committee to talk to Professor Raymond and her team about this.

I think advance care planning gives us the opportunity to ask, 'What is important for you? Where do you want to be? How do you want to die in terms of place and who is around you?' By goodness, we can then try to mobilise as much as we can to provide that support and we have congruence. I think that is important. I seek leave to table the evaluation document. It is a worthwhile read from the Office of Advance Care Planning.

CHAIR: Is leave granted? There being no objection, leave is granted.

Dr Parker: I think that is an important component.

CHAIR: There is no doubt about it. The same nurse who spoke recently said that 90 per cent of those hundreds of patients she was looking after did not have an advance care plan.

Dr Parker: And we do not ask.

CHAIR: We will get copies of that.

Ms PEASE: I thank everyone very much for coming. Thank you for the great work you do in the community. I want to talk about education, which is something that you raised extensively in your submission. Much of that has been outlined by Dr Cruikshank. There is no specialist training like the training a doctor has to do to become an anaesthetist or a specialist orthopaedic surgeon? There is not a title of specialist palliative care doctor?

Dr Parker: There is a training program. There is quite a successful training program through the College of Physicians. If I can refer you to our first document that we tabled re the palliative medicine training pathway, there is that training through the College of Physicians. There are two components. One is doing that through a physician program where you start off as a basic trainee, do the exams and then become a specialist. That is approximately a six-year program. The other pathway we have, which has really been borne out of the need for more specialists in the field, has been through a chapter. For example, I have come from a general practice background. My interest has been in palliative care. I have done my fellowship in general practice and then I changed direction and did the fellowship in palliative medicine. We have anaesthetists. Ross Cruikshank, who is on the line, is an oncologist, who would do palliative care. There is a dedicated training program for medicine in terms of the other complexities. In terms of nursing and allied health, it is more porous and that is the struggle.

Ms PEASE: That goes to my next question. What services or training opportunities are there for the on-the-ground service providers such as nurses?

Dr Parker: If you look at the components of it, we emphasise the need for clinical educators. We do not have that luxury. We do not have the ability to workforce develop and create those training platforms. It is about those services that have the ability to help their staff through that process—where nurses can do graduate training programs, where they can do certificates. It is costly, it is time-consuming and it is hard. I do not think that as a structure we support them to get that training.

Ms PEASE: There are certificate programs or graduate diploma opportunities?

Dr Parker: Yes, there are.

Ms PEASE: Currently, many of the nursing and allied health service providers are learning on the fly, on the job.

Dr Parker: That is fair to say. I agree and I think that makes it very difficult. We need to invest in a specialist workforce to be able to do that and support that learning environment by creating those training positions.

Dr Welch: There are clinical nurse educators in the most significant health services who have a small role in helping to roll out some small education. Our particular service has nurse practitioners who go out into the communities. They go into RACFs and provide ongoing education. We have committed to the RACF communities, because their nurses change so frequently. If we do a year's education in the district nursing homes this year, you can probably bet that 50 per cent of the nurses would have left those sites within a year. We have to educate every single year.

We have a policy that a nurse practitioner visits a nursing home for every nursing home discharge, if we can, within a week of discharge so that the RACF nurses, at least by telephone or in person, have a nurse who understands what that patient is about and what their needs are and to ensure that the staff in the nursing home are comfortable with those needs. That is our particular service and our commitment—but, again, that requires resourcing.

The education programs through the Centre for Palliative Care Research and Education based at Royal Brisbane do have a number of diplomas that people can do online. There are masters that nurses and allied health people and doctors can do, but not in Queensland. They are based in southern universities. They are available, but they are expensive.

Ms PEASE: Further to that, you talked about nursing homes and aged-care facilities. I am not sure whether you can answer this. Is there any palliative training that the AINs or the people who work in those facilities undertake?

Dr Welch: None whatsoever. These women and men may just do a standard certificate of nursing required for that position in that nursing home. Anything extra would require management to dedicate resourcing to a champion in that nursing home. This is what our particular service has been trying to find: champions in each service where that person would take the lead in that facility—but, again, they leave.

Ms PEASE: Further to that, in nursing homes or aged-care facilities where they do have palliative patients, there is no requirement for the staff to have any palliative experience.

Dr Welch: There is no requirement. That is correct.

Dr Parker: It is very district and service dependent and facility dependent. In our area we cover approximately 90 nursing homes—approximately 7,000 beds. We have a structure which we have worked hard to deliver with a nurse practitioner and two FTE nurses. We have developed a link nurse project. Ms Pease, I think you would be aware of the Wynnum model that we have looked at as well.

Ms PEASE: Absolutely.

Dr Parker: I think they are few and far between. Unless there is dedicated resourcing and commitment to developing the staff in those services, it is hard. It is not universal throughout the state. That is why we talked about developing an RACF centre of excellence where we can, because they are the hospices of the future—we have to face that reality—and we need to give the best care possible to our aged population. It is not something that we should park on the side, but we need to scale that across the state.

Ms PEASE: I have run out of time, but I did want to particularly acknowledge the great work at the Blue Care facility—it is fantastic—and congratulate the team for allowing the rest of the staff at Blue Care to run through their palliative care centre to get some experience.

Mr O'ROURKE: This has been excellent listening to the experts. My question is to Dr Whan in regard to rural and regional Queensland. What are a couple of key things that the committee really needs to know in trying to provide palliative care through rural and remote Queensland?

Dr Whan: The challenges are significant. I am not telling the committee anything you do not know. My United States colleagues have a hierarchy of regional, rural, remote and frontier—they tack on 'frontier'. Some of the communities I have visited I would affectionately term 'frontier', not in the least in a pejorative way. Those communities call in their resources and in many cases provide an amazing level of care to their community members by pulling resources together. That is patchwork and variable again.

Chair, you mentioned the vital role of nurses in this area. If I could make a plea: for the past 12 years I have been the only designated palliative medicine specialist for a population of about 400,000 people across a service area of about 200,000 square miles. On Palliative Care Australia workforce guidelines—two per 100,000—there should be eight of me. I would be absolutely useless if it were not for the wonderful advanced practice nurses who are there, boots on the ground, 365 days a year, who as members of their local community understand the particular issues, challenges and opportunities within the community. We need to do whatever we as a community can do to support those nurses—sometimes individual nurses, sometimes teams of nurses. As other members of the group have said, they often see to their own education. They enrol in graduate diplomas through Flinders University or whatever it may be. They are the key to the on-the-ground provision.

One of the roles I feel I have particularly provided for them—my title is outreach and support—is a support role in being a specialist medical colleague to those nurses and providing informal education and advice. I have been available by telephone and more recently via telehealth, with Queensland Health's wonderful telehealth infrastructure. I do not know whether committee members can recall the palliative care seminar when I stood up and talked about doing telehealth on my phone. Mr O'Rourke, it was within your local area where the patient was involved.

To be able to provide that support I think has been a key part of keeping those advanced practice nurses energised with a sense of support. If they do not get support from specialist palliative care services and multidisciplinary palliative care services, and especially access to specialist palliative medicine advice and support, they are tempted or pushed sometimes to work outside their scope of practice which is not appropriate, and they do not want to do that. There are big challenges. There is a lot of goodwill in local communities. Advanced practice nurses have a vital role.

Mr McARDLE: Thank you, Dr Parker, and your colleagues. You are very highly qualified and you have taken up a great deal of your day to be here today, and we do appreciate that. Dr Broadbent, you mentioned HammondCare studies. Is that right?

Dr Broadbent: Yes, HammondCare was the group I used to work with.

Mr McARDLE: Do they have public papers available that we can look at?

Dr Broadbent: Yes. There have been a couple—

Mr McARDLE: Just yes or no.

Dr Broadbent: Yes.

Mr McARDLE: Could you give a citation to the secretariat because that may help us in understanding how things are practised in New South Wales. My second question is this: is there a document that outlines the distinction between Queensland and other states in regard to palliative care—what is provided and what is not provided—to give us a comparison as to maybe where we should be heading to or looking to in relation to what we can do?

Dr Broadbent: I do not think there is a document. Palliative Care Australia has the national guidelines. I do not think PCQ have done one locally. They probably need resourcing to do that, because I think that is a very good point.

Mr McARDLE: It is a state-by-state jurisdiction issue. That raises the question of the inequities that can occur between living at the Tweed or on the Gold Coast. That is a very important point to try to equalise access to treatment across the nation. Sorry, Dr Welch, you were going to point out my error.

Dr Welch: No. There is no error. I just want to qualify that most of us have moved between health services in the state as well. It is not equitable from health service to health service.

Mr McARDLE: That was my next point. I want to go back to the paper. You make it very clear that the HHSs are critical in relation to palliative care being delivered. Most of you are linked directly or indirectly to a HHS—Metro North, Metro South or, the best in the world, the Sunshine Coast HHS. My concern is this: HHSs have a different budget, different demographic, different area to try to deal with and different priorities within the HHS. How do we get to a point where we have a program that is equal across the HHSs, because they are the ones who are going to deliver the services more likely than not to Queenslanders facing the need for palliative care? How do we move to a point that we get that equity in the HHSs, understanding by the relevant organisational bodies in the HHSs and delivery on the ground that is best for all Queenslanders, as best we can? It is a very simple question!

Dr Parker: Engagement—engagement with expert clinicians on the ground with us.

Mr McARDLE: That is fine.

Dr Good: I think what you are asking is this: we can all ask for extra workforce but what does that mean? I think the key is to have accountable key performance indicators which are minimum standard for every HHS, leave them with those key performance indicators and say, 'You have to reach these.' I will give some simple examples that I think are really important. You talk about integration between hospitals and community. I think every palliative care patient in the community who needs to come into hospital for end-of-life care or symptom control should be able to have direct access to an inpatient bed and not have to go through an emergency department. They should have direct access 24 hours a day, seven days a week to an inpatient bed and not have to go through an emergency department.

CHAIR: By that do you mean a palliative care unit?

Dr Good: No, not necessarily. Mostly a palliative care unit is a start. Not everywhere is going to have a palliative care unit. There are a lot of hospitals throughout Queensland that have dedicated palliative care beds that are not palliative care units—for example, in rural areas.

The next example is that every cancer multidisciplinary team meeting that occurs in hospitals should have a dedicated palliative care specialist who is able to attend that meeting. That does not happen now because there is not the staffing for that. There are high-level cancer services throughout Queensland that do not have very much or any palliative care access at those meetings.

The next one is that every palliative care patient should have access to specialist palliative care 24 hours a day, seven days a week. I am not saying that these examples are easy things to reach; I am saying that they are really high-standard things. That does not necessarily mean face-to-face after hours. It could be through telehealth. It could be by telephone. People do not have access to this at the moment.

Mr McARDLE: Dr Good, I agree with that. I am not trying to downplay your comments. I want to understand on the ground how you make it happen because it has to be driven by, I would have thought to a large extent, Queensland Health and the community. How do we actually do it? Do we need to set up an overarching body of some sort? Do we need to consider the budget? Do we need to consider putting in KPIs? We are all in that 100 per cent cohort who are going to die. We cannot get away from that. That can only get worse as time goes by because of comorbidities that are now creeping into anybody with diabetes and the like. We are going to have more complex needs in relation to palliative care. Unless we start that process now, we are going to find ourselves having this battle in 10 years time. Is there something that we can look at that says, 'This is a program we can move forward with,' in relation to HHSs? I am not trying to be smart. I am trying to get down to what I see has to happen on the ground.

Dr Parker: May I offer the following, please?

Mr McARDLE: Absolutely.

Dr Parker: We actually do have a system. We have a clinical services capability framework that has been mandated by Queensland Health and that is applicable in each HHS, whether it is a public or a private hospital system. It says that, if we have this level cardiology service or this level cancer service, there needs to be a matched service to support them—for example, palliative care. If we can go back to that and actually say, ‘How do you implement this in an accountable way?’ For example, in Rockhampton, there is a level 5 cancer service.

Mr O’ROURKE: That is right.

Dr Parker: At the moment it is self-reporting. They talk about a level 5 palliative care service. There is no palliative care physician at all. There is a bits-and-pieces patchwork approach to delivering palliative care. I think we need to make the system accountable for that.

We support our colleagues. With all due respect, Peter Whan has done this for a long time and what we have said is, ‘That’s fine. Let’s leave it as it is,’ without actually saying, ‘Hang on, but your services capability framework says that you need this level of support in order to deliver that, and there are accreditation consequences and there are service provision consequences if people do not match that.’ If they have a level 5 service with no palliative care service, they cannot practice in that sense. They cannot have that level of care without us.

Mr McARDLE: Dr Parker, you are saying there is a framework involved—

Dr Parker: Correct. Let’s use it.

Mr McARDLE:—but it is not being properly utilised.

Dr Parker: Correct.

Mr McARDLE: We need to get back to that core document—

Dr Parker: Exactly.

Mr McARDLE:—and start focusing on what is needed and build upon that as well.

Dr Parker: I agree.

Mr McARDLE: My last question is this: clinical trials, I think, are pivotal in relation to palliative care.

Dr Parker: Yes.

Mr McARDLE: The public—and I am one of them—do not quite get palliative care. They get VAD, but they do not get palliative care. What trials are being undertaken at the moment, in a very general sense, to inform the committee as to what is taking place?

Dr Good: There is actually a Queensland Palliative Care Research Group which is doing trials. Maybe the best thing I can do is send the committee a list of trials that are taking place that I know of in Queensland. For example, we do a lot of clinical trials across the Mater and St Vincent’s. At the Mater we have a Medical Research Future Fund grant to do a trial about the use of medicinal cannabis in palliative care. We are doing trials about the use of medication to prevent delirium at the end of life, for example. I can give you a list of trials that are going on across those groups.

CHAIR: In the interests of time, we might need to get that list.

Dr Parker: May I table one document to show you the practicality of what clinical trials do?

CHAIR: Is leave granted? There being no objection, leave is granted.

Dr Parker: Caring at home—it is a national program.

Mr McARDLE: I would love to get this panel back, because I have thousands of questions I would like to ask.

CHAIR: Yes. We are out of time and I appreciate that we have other people here for the next briefing. I want to finish with a question to you. In your experience, is there a point in time where a palliative care patient might well seek voluntary assisted dying?

Dr Whan: My quick answer is yes. I have seen it over and over again. I think the question is: how do we respond to that? I have given anecdotes of how I believe, in responding respectfully and appreciatively, I have been able to address the issues that have arisen—but the quick answer is yes.

CHAIR: We are going to have to get you back. We have a wonderful group in front of us and on the phone. I appreciate all of your time in this very important space and, again, in this very important inquiry. I thank each of you. The committee will be in touch. We may well seek another

briefing. We have run out of time this morning. We have gone well over. Thank you all for being here. Thank you to our doctors on the phone. We do appreciate your time and expertise in sharing some of your observations. It is very helpful for our inquiry. I declare this briefing closed.

The committee adjourned at 10.47 am.